

## Special Issue: NCI Member Profiles

Twenty-three states plus the Regional Center of Orange County in California are currently participating in National Core Indicators (NCI). In addition, three Bay Area Regional Centers in California are in the process of piloting NCI. This issue of the Indicator presents brief descriptions of each state and regional project. These summaries were compiled from NCI Steering Committee representatives, some of whom are just beginning implementation and others who have been collecting data for many years. Although tenure and approach vary across states, all share a common commitment to gathering system-level performance data and using this information to improve the quality of services and supports for people with intellectual disabilities.

### Alabama Participation in NCI: five years

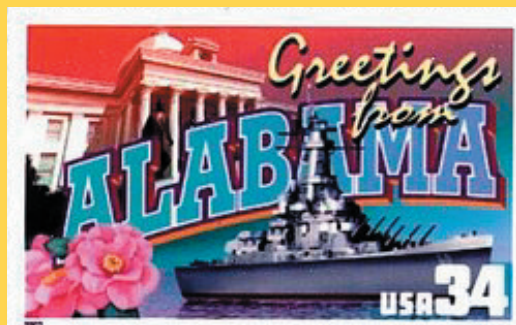
Since Alabama closed three of four of its residential institutions, the Department of Mental Health and Mental Retardation (DMR) has used NCI Consumer and Family/Guardian Surveys pre- and post-discharge to demonstrate the effects of closure, which include an increase in community involvement on the part of consumers.

The DMR also:

- Presents NCI survey information to the state Legislature for performance-based budgeting.
- Uses survey information to inform the process of setting goals, objectives and benchmarks for the Division's Quality Enhancement Plan and three-year Strategic Plan

- Employs Consumer Survey information as a quality measure and national benchmark for satisfaction with services and the service delivery system in SMART (Specific, Measurable, Accountable, Responsive, Transparent) Planning, a gubernatorial strategic priority for state wide planning.

**State Website:** <http://www.mh.state.al.us/services/mr/index.htm>



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## Arizona Participation in NCI: nine years

Arizona was one of the original pilot states for NCI and has participated each year since. Based on experience, the Division of Developmental Disabilities made a decision to administer the various NCI survey tools on alternate years. During the first of a two-year cycle, Arizona now uses the Consumer Survey, Adult Family and Provider Surveys. In the second year, the Child Family and Family/Guardian Surveys will be conducted. Other data elements, including mortality, incident, and financial reports are provided as frequently as possible, if not every year.

team then develops strategies on how best to implement policy or other system change. At least once per year, the Division creates a

report that the Support Coordinators share with the consumers and their families. In addition, data on satisfaction and on services provided by case managers, are shared with the legislature.



Using NCI data, a state quality management team identifies 3 or 4 main areas for improvement. The

**State Website:** <http://www.de.state.az.us/ddd/>

## Arkansas Participation in NCI: one year

As a new NCI state, Arkansas has begun conducting 400 Consumer Surveys, 1,000 Family/Guardian and Adult Family Surveys, and 1,000 Child Family surveys. Staff and Board Surveys have been mailed to providers. Since NCI is part of the Division of Developmental Disabilities Services (DDDS) quality enhancement process for the waiver, the state is only working with waiver recipients this year.

When the Centers for Medicare and Medicaid Service made an on-site visit last year, they noted that certain critical data required under the quality framework was not being collected through the survey tool that Arkansas had been using. Pam Fowler of DDDS recalls, “Looking at the crosswalk of the framework and the NCI tools, it was apparent that the NCI survey is much more effective [than current data collection tool] in gathering data.” Having cited this in its response to CMS, Arkansas received a favorable review, and proceeded to launch its NCI surveys.



**State Website:** <http://www.arkansas.gov/dhhs/ddds/NewWebsite/index.html>

## Bay Area Regional Centers of California (Golden Gate Regional Center, San Andreas Regional Center, Regional Center of the East Bay) Participation in NCI: entering their second year

In its first year of participation in NCI, Bay Area Regional Centers surveyed people who moved out of the Agnews State Developmental Center and a random sample of waiver participants. According to Kraig Nagel of San Andreas Regional Center (SARC), the Bay Area Regional Centers and a number of review commissions are in the midst of studying the initial data.

Nagel anticipates that the process of gathering pre-survey and background information will be streamlined when the Centers begin to use a new state information system called CADDIS, expected to save months of legwork.



## Regional Center of Orange County, California Participation in NCI: five years

The Regional Center of Orange County (RCOC) has revised some of its Guiding Principles, thanks to participation in NCI. Data from 2002-2004 revealed a consistently low percentage of families reporting that their children had access to and were participating in community activities. In health care, about half of the region's consumers were not attending annual physical checkups, and a lower percentage received regular OB/GYN and six-month dental exams. In employment, many consumers were working in facility-based jobs, such as workshops, earning a lower hourly wage than those in community-based jobs, and expressing desire for improvement in these areas. After performing a crosswalk between its Guiding Principles and the Core Indicators, RCOC's Board of Directors and Management Team revised two existing Guiding Principles and created a new one.

- Old Guiding Principle: Consumers have access to essential health services.
- Revised Guiding Principle: Consumers and their families have knowledge of their health care needs, access to qualified medical communities, and support necessary to utilize recommended health services.
- Old Guiding Principle: Consumers have the opportunity and support to work.
- Revised Guiding Principle: Consumers have the opportunity and support to work in employment settings that are meaningful to them, that are valued by the community, and in which they are appropriately compensated.
- New Guiding Principle: Consumers and their families have knowledge of, access to and

opportunity for participation in any community activities and resources of their choosing.



## Connecticut Participation in NCI: nine years

Connecticut regional offices are currently focused on improving timeliness and consistency in NCI data collection by streamlining the consumer process. In the past, as many as 20 different staff from regional and central offices volunteered to conduct some 450 interviews per year. Now, the Department of Mental Retardation (DMR) has assigned Quality Monitor staff to its Regional Quality Improvement Divisions, to perform the interviews. The DMR has also hired a full-time planner to improve on organization of NCI data and its delivery to quality councils for analysis.

The NCI project and associated data are significant components of Connecticut's overall quality management program. Specific indicators have

been incorporated into the State's larger Quality Service and System Review program and serve as performance benchmarks that are reviewed year to year. Analysis of specific NCI results are also shared with the Regional Quality Councils, and used in department-wide goal setting.

**State Website:** <http://www.dmr.state.ct.us/>





## Delaware Participation in NCI: six years

In the past year, Delaware's Division of Developmental Disabilities Services conducted NCI Consumer and Mortality Surveys while working to develop performance measures with a Real Choice Systems Change Grant from the Centers for Medicare and Medicaid Services (CMS), with technical assistance from HSRI.

The performance measures will be used to inform the overall quality management system. The new indicators were identified by stakeholders as important and are designed to cover the assurances that CMS requires states to track and report. Many of the measures are tied in to NCI data and will be used to help with the new 373Q annual reporting form. Information from NCI surveys is posted on the agency's website, and presented to advocacy groups and the Governor's advisory committee.



**State Website:** <http://www.dhss.delaware.gov/dhss/ddds/index.html>

## Georgia Participation in NCI: one year

In its first year of NCI participation, Georgia completed 400 Consumer Survey interviews, received over 500 completed versions of the Adult Family and Family/Guardian Surveys, and yielded responses from 79 providers to Provider Staff Turnover and Board Membership Surveys.

Before joining NCI, Georgia held a series of stakeholder meetings to identify a list of priority MR/DD performance indicators. According to Megan Brooks of the Division of Mental Health, Developmental Disabilities and Addictive Diseases, "Participation in the NCI program will allow us to gather data on a majority of these indicators. Because the NCI indicators are closely aligned with the CMS Quality

Framework, the NCI program will also allow us the ability to better assess waiver services."

**State Website:** <http://mhddad.dhr.georgia.gov/portal/site/DHR-MHDDAD/>



## Hawaii Participation in NCI: five years

In Hawaii, a Quality Assurance Subcommittee meets quarterly to review NCI data and issue recommendations for improvements in Hawaii's system of supports for people with developmental disabilities. This fall, they are in the process of adding four additional members (one on Oahu, one on Maui and two from the island of Hawaii), with the aim of full statewide representation.

An internal Quality Assurance/Quality Improvement Team at the Department of Health's Developmental Disabilities Division (DDD) is currently examining the compatibility of DDD quality standards for waiver providers and case management with the Quality Framework of

the Centers for Medicare and Medicaid Services, and reviewing NCI outcome areas that support the DDD's strategic planning initiatives.

**State Website:** <http://www.hawaii.gov/health/disability-services/developmental/index.html>



## Kentucky Participation in NCI: seven years

Kentucky surveys over 3,500 people who receive services, and has committed its experience to videotape. In the past six years, the Interdisciplinary Human Development Institute of the University of Kentucky has developed three videos to assist in training survey interviewers, available to other states through HSRI.

Kentucky's Division of Mental Retardation recently completed two general population comparisons to examine how consumers who receive state-funded services correspond to a general sample of Kentuckians at large. Telephone surveys of randomly selected Kentuckians included items from the NCI Consumer Survey.

**State Website:** <http://mhmr.ky.gov/kdmhmrs/default.asp>



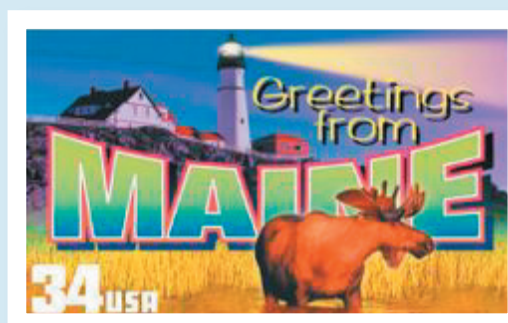
## Maine Participation in NCI: four years

Since 2004, Maine's Office of Adults with Cognitive and Physical Disabilities has administered the Quality of Life interview, a version of the NCI Consumer Survey that OACPD adapted in conjunction with the Office of Integrated Services/Quality Improvement. Recently, Maine developed a pilot co-interviewing tool that engages consumers, families and community members in an in-depth evaluation of community inclusion and consumer satisfaction with participation in various activities.

Future plans for Maine may include use of the co-interview pilot on a larger scale, participation in a mortality review, a quality assessment of current survey tools and methodologies with stakeholders, and training of self-advocates as interviewers for surveys that are cur-

rently administered by contracted agency staff. Maine uses data collected from survey tools to monitor areas of community inclusion, case management, and service satisfaction for quality improvement purposes for the Office of Adults with Cognitive and Physical Disabilities.

**State Website:** <http://www.state.me.us/dmhmrsl/>



## Massachusetts Participation in NCI: seven years

The Massachusetts Department of Mental Retardation (DMR) contracted with HSRI to conduct 1,000 consumer interviews. A major impetus was to gather data for pending lawsuits against the state that claim community services and supports are ineffective. The DMR views the NCI data set as one of the most compelling arguments on the table about quality in the community system and the benefits people derive from it.

Massachusetts uses NCI data to produce an extensive quality assurance report that is posted on the DMR website. The state has received positive feedback from the Centers for Medicare

and Medicaid Services about incorporating NCI data into the state's quality management system.

**State Website:** <http://www.mass.gov/dmr>



## New Mexico Participation in NCI: less than one year

At NCI's Steering Committee meeting in San Diego in February, New Mexico reported that they had not yet begun to conduct any surveys, but were excited to be on board with the rest of the NCI participants.

New Mexico is developing a new provider survey tool and, according to Cathy Stevenson, Deputy Director of the Long Term Services Division of the Department of Health, a copy should be ready to share at the 2007 Steering Committee meeting. Based on the NCI Consumer Survey, the instrument will address continuous improvement requirements for the settlement of a class action law suit. Stevenson says its intent is to improve upon an instrument that has proven cumbersome in practice.

**State Website:** <http://www.health.state.nm.us/ddsd/index.htm>



## North Carolina Participation in NCI: seven years

In its early years, North Carolina's Developmental Disability Services analyzed survey results in relation to the state only. Recent NCI data have been broken out for each of 30 local governmental management entities (LMEs), with individual analyses that correlate each LME's data to that of all others, and to the state average.

NCI data have been shared at state-sponsored Case Management and Best Practices Conferences and with the state's General Assembly, which receives a system performance report regarding ways in which the Division of Mental Health, Developmental Disabilities and Sub-

stance Services is addressing performance measures that the General Assembly developed.

**State Website:** <http://www.dhhs.state.nc.us/mhddsas/>





## Oklahoma Participation in NCI: five years

Oklahoma has been working to renew its community waiver this year. As part of the process, The Developmental Disabilities Services Division (DDSD) is scrutinizing Consumer and Adult Family Survey data collected during its years of participation in NCI.

Genny Gordon of the DDSD forecasts that at next year's NCI Steering Committee meeting, Oklahoma will be able to report on how NCI data fit into the DDSD's quality management system, how the information will be used and with whom they will share it. According to Gordon,

Oklahoma hopes to increase its usage of NCI data to meet Centers for Medicare and Medicaid Services requirements.

**State Website:** <http://www.okdhs.org/programsandservices/dd/>



## Pennsylvania Participation in NCI: nine years

This year Pennsylvania's Office of Mental Retardation added a supplement to the Essential Data Elements (EDE) survey it uses to interview people receiving services. (NCI questions form a portion of the EDE for persons living in State Centers who are unable to communicate with the interviewing team, the supplement allows a surrogate to respond. Instead of trying to elicit the respondent's opinions or feelings, questions aim to document the feelings of the State Center resident as seen through the eyes of the respondent.)

Example of a 2-part supplement question:

**Does it appear that this person likes their work (paid or volunteer) or other day activities programming outside their living area?**

**What does the person do in terms of be-**

**havior or expression to suggest how he/she feels about work/day activities?**

Pennsylvania has also been piloting a Community Rehabilitation Survey. It includes questions from NCI Consumer and Family Surveys, and is designed to generate data on program characteristics of agencies that support adults outside of typical services.

Pennsylvania surveys approximately 6,700 people receiving services a year through their IM4Q process. Of these, approximately 1,400 people are also surveyed using the NCI tool. The NCI Consumer sample is composed of 30 randomly selected adults in each of our 46 county MH/MR programs. Data extracts are prepared for each County program which allows the counties administrators to see their NCI Consumer results compared to the results of other counties in their Region, all counties across the state, and to other

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## Pennsylvania Participation in NCI: nine years (continued from page 9)

States. Counties are responsible for using this and family survey data for quality improvement purposes and can access and analyze their data through a statewide data warehouse.

State Officials use NCI for reporting to CMS, and for making improvements across the system. For example, state QA staff prepared a report for our State Quality Council that demonstrated the difference in satisfaction and outcomes for adults living with families or in community programs based on NCI Adult Family and Family Guardian Surveys. Data on NCI indicators are also available on line for providers to compare their aggregate results and performance to other provider

agencies across the state.

**State Website:** <http://www.dpw.state.pa.us/Disable/MentalRetardationServices/>



## Rhode Island Participation in NCI: seven years

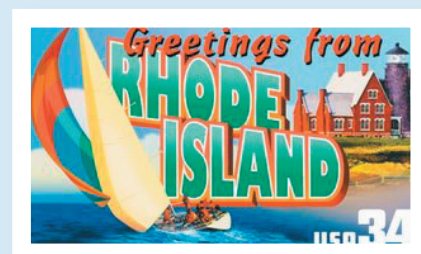
Rhode Island's Division of Developmental Disabilities contracts with Parents and Friends for Alternate Living (PAL) to conduct the NCI Consumer Survey. PAL has issued a five year report and disseminated it statewide to all provider and advocacy organizations. It is available on their website: <http://www.pal-ri.org/>

The DDD uses some NCI measures for its annual budget document to provide information on performance measures to the Governor and Legislature.

At the request of Rhode Island's statewide stakeholder group, the Quality Consortium, the DDD's Incident Management Trends Analy-

sis Committee was expanded to include representatives from various advocacy and provider organizations. This committee reviews data reported on all incidents and is working to identify preventive strategies in the areas of neglect, sexual abuse and psychiatric admissions.

**State Website:** : [http://www.mhrh.state.ri.us/developmental\\_disabilities.htm](http://www.mhrh.state.ri.us/developmental_disabilities.htm)



## South Carolina Participation in NCI: four years

South Carolina's Department of Disabilities and Special Needs conducts Consumer, Staff Turnover and Board Surveys at the same time as statewide Provider Quality Assessments. The state is currently working on quarterly and year-to-date reports. Individual reports are given to state providers for review so that they may compare themselves with peers and national benchmarks.

**State Website:** <http://www.state.sc.us/ddsn/>



## South Dakota Participation in NCI: four years

South Dakota's Division of Developmental Disabilities has returned to the NCI program this year, following a two-year hiatus. In 2002/03, all NCI surveys were completed. To allow for close comparisons, this process is now being repeated with the same instruments and the same providers. Carol Ruen of the DDD says that everyone involved is eager to view the results.

South Dakota's reports are made publicly available at: <http://www.state.sd.us/dhs/dd/Division/NCI%20Reports.htm>.

**State Website:** <http://www.state.sd.us/dhs/dd/index.htm>



## Texas Participation in NCI: one year

The Texas Department of Aging and Disabilities Services (DADS) is in the process of completing a report for their first year in the NCI program. It will include results for several different waiver programs. While DADS uses the NCI survey for persons with developmental disabilities, it employs

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## Texas Participation in NCI: one year (continued from page 11)

the Participant Experience Survey (PES) for other populations. A request for proposals was issued this year, to conduct 2,500 face-to-face surveys and 2,500 mail surveys.

**State Website:** <http://www.dads.state.tx.us/>



## Vermont Participation in NCI: nine years

Vermont, unlike all other NCI members, began conducting surveys of consumers before joining NCI, and therefore elected to continue using their original survey tool. Two years ago, they worked to align their survey with NCI's.

Vermont recently received a Real Choice Quality Assurance/Quality Improvement grant to assist in improving the incorporation of data from surveys into a new quality management review process. According to June Bascom of the Division of Developmental Services, the grant will help the state enhance the quality of data collection and reporting in the areas of staff stability and critical incident reports.

**State Website:** : <http://www.dad.state.vt.us/>



## Washington Participation in NCI: seven years

Washington State economizes by combining additional questions with the established NCI survey process. According to Lisa Weber of the Division of Developmental Disabilities, "This way, we have



a cost-effective vehicle for gathering information on issues that are important to the Division. It also helps prevent 'survey fatigue' amongst consumers and families." Weber encourages other states to use the additional questions and produce comparative data. They include:

- consumer perception of/satisfaction with medical personal care and respite providers.
- consumer perception of case management services.
- waiver-specific satisfaction with services
- survey of people who are waitlisted (receiving case management only)

- children's services added to NCI Consumer Survey

**State Website:** <http://www.l.dshs.wa.gov/ddd/index.shtml>



## West Virginia Participation in NCI: five years

West Virginia's Division of Developmental Disabilities uses NCI to identify problems and act upon them, according to Beverly Dorcas of the DDD. Examples of actions taken include a new grievance policy and incident management system, and a pilot web-based incident reporting system. A Quality Assurance Council for waiver programs examines NCI data and has used it to recommend improved dissemination of information.

**State Website:** <http://www.wvdhhr.org/bhhf/mrdd.asp>



## Wyoming Participation in NCI: five years

A recent focus in Wyoming is to create reports for providers of seven or more persons. From an NCI and State of Wyoming Consumer Satisfaction Report, information is separated out to create reports for individual large agencies. To protect confidentiality, no fewer than seven persons are

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## Wyoming Participation in NCI: five years (continued from page 13)

included in any one report. They are sent to agency CEOs, directors, and lead individual service coordinators, and often used to help with CARF accreditations and statistical comparisons against national and state averages. Wyoming's incident reporting system became web-based this year. Via a web site at the University of Wyoming, witnesses can securely add follow-up information. DDD Program Integrity staff may access the incident on the server and enter further data. The database produces monthly reports for the DDD concerning specific individuals, date ranges, and agencies.

**State Website:** <http://wdh.state.wy.us/DDD/index.asp>



For more information, visit the NCI website at [www.hsri.org/nci](http://www.hsri.org/nci)

